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THE RESEARCH ON ALZHEIMER'S DISEASE AND
INDEPENDENCE FOR OLDER AMERICANS ACT OF 1990

OCTOBER 9 (legislative day, OCTOBER 2), 1990.—Ordered to be printed

Mr. KENNEDY, from the Committee on Labor and Human
Resources, submitted the following

REPORT

[To accompany S. 2602]

The Committee on Labor and Human Resources, to which was referred the bill (S. 2602), to amend the Public Health Service Act to provide assistance for biomedical and health services research, education, treatment programs and for other purposes relating to Alzheimer's Disease and related disorders and to enhance the independence of older Americans, having considered the same, reports favorably thereon with an amendment, and recommends that the bill as amended do pass.

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The amendment is as follows:

Strike all after the enacting clause and insert the following:

SECTION 1. SHORT TITLE.

This Act may be cited as the "Research on Alzheimer's Disease and Independence For Older Americans Act of 1990".

TITLE I—RESEARCH CONCERNING ALZHEIMER'S DISEASE AND RELATED DISORDERS

SEC. 101. ALZHEIMER RESEARCH CENTER CORE GRANTS.

Title IV of the Public Health Service Act is amended by inserting after section 445F (42 U.S.C. 285e-8) the following new section:

"SEC. 445G. ALZHEIMER RESEARCH CENTER CORE GRANTS.

"(a) IN GENERAL.—To complement and expand the program of the Alzheimer's Disease Research Centers authorized in section 445, the Director of the National Institute on Aging shall—

"(1) award Core Center Grants to university medical centers to encourage and to facilitate the development of innovative multidisciplinary research concerning Alzheimer's Disease and encourage investigators to enter into the field of Alzheimer's Disease research, such grants shall be used to support—

"(A) patient assessment units that facilitate clinical research and the development of new treatment techniques including clinical drug trials;

"(B) patient registries and Alzheimer's Disease patient tissue and brain banks and control studies;

"(C) the training of new investigators;

"(D) public education and information dissemination; and

"(E) support collaboration between institutions for research and other activities; and

"(2) enter into grants, contracts or cooperative agreements with Alzheimer's Disease Research Centers established under section 445, or entities receiving financial assistance under paragraph (1), for the provision of diagnostic and treatment service and research for Alzheimer's Disease and related disorders at Satellite Clinics, such clinics to be targeted to minority, rural or other underserved populations.

"(b) APPLICATION.—Each entity desiring to receive a grant or enter into a cooperative agreement under this section shall prepare and submit, to the Director of the Institute, an application at such time, in such manner and containing such information as the Director may reasonably require.

"(c) AUTHORIZATION OF APPROPRIATIONS.—There are authorized to be appropriated to carry out this section, \$40,000,000 for fiscal year 1991, and such sums as may be necessary in each of the fiscal years 1992 and 1993."

TITLE II—EXTENSION OF PROGRAM REGARDING ALZHEIMER'S DISEASE

(a) PROGRAM REGARDING ALZHEIMER'S DISEASE.—

(1) NUMBER OF GRANTS.—Section 398(a) of the Public Health Service Act (42 U.S.C. 280c-3(a)) is amended in the matter preceding paragraph (1) by striking "shall make" and all that follows through "grants" and inserting the following: "shall make not less than eight nor more than 15 grants".

(2) COORDINATION OF SERVICES.—Section 398(a)(1) of such Act (42 U.S.C. 280c-3(a)(1)) is amended by striking "by public and private organizations" and inserting "with public and private organizations".

(3) AUTHORIZATION OF APPROPRIATIONS.—Section 399A(e) of such Act (42 U.S.C. 280c-5(e)) is amended—

(A) by striking "there is" and inserting "there are"; and

(B) by inserting before the period the following: ", \$20,000,000 for fiscal year 1991, and such sums as may be necessary for each of the fiscal years 1992 and 1993".

(b) EFFECTIVE DATE.—The amendments made by this section shall take effect on October 1, 1990, or on the date of enactment of this Act, whichever occurs later.

TITLE III—TASK FORCE ON AGING RESEARCH

SEC. 301. ESTABLISHMENT.

(a) COMPOSITION.—To enhance the coordination of Federally supported aging research, particularly as it relates to Independence for Older Americans, the Secre-

tary of Health and Human Services (hereinafter referred to in this title as the "Secretary") shall establish a Task Force on Aging Research (hereinafter referred to in this title as the "Task Force"). The Task Force shall be composed of—

- (1) the Assistant Secretary for Health;
- (2) the Surgeon General of the United States;
- (3) the Assistant Secretary for Planning and Evaluation;
- (4) the Director of the National Institute on Aging, and the Directors of other components of the National Institutes of Health as may be appointed by the Secretary;
- (5) the Commissioner of the Administration on Aging;
- (6) the Commissioner of the Food and Drug Administration;
- (7) the Chief Medical Director of the Department of Veterans Affairs;
- (8) the Director of the Alcohol, Drug Abuse, and Mental Health Administration;
- (9) the Administrator of the Health Care Financing Administration;
- (10) the Commissioner of the Social Security Administration;
- (11) the Director of the Agency for Health Care Policy and Research;
- (12) two Members of the House of Representatives appointed by the Speaker of the House in consultation with the Minority Leader, and two members of the Senate appointed by the Majority Leader in consultation with the Minority Leader, not more than one of whom from each body shall be members of the same political party; and
- (13) three members of the general public, to be appointed by the Secretary, that shall include one representative each from—
 - (A) a nonprofit group representing older Americans;
 - (B) a private voluntary health organization concerned with the health problems affecting older Americans; and
 - (C) a nonprofit organization concerned with research related to the health and independence of older Americans.

(b) **CHAIRPERSON.**—The Secretary, acting through either the Assistant Secretary for Health or the Director of the National Institute on Aging, shall serve as the Chairperson of the Task Force.

(c) **QUORUM.**—A majority of the members of the Task Force shall constitute a quorum, and a lesser number may hold hearings.

(d) **MEETINGS.**—The Task Force shall meet periodically at the call of the Chairperson, but in no event less than twice each year.

(e) **APPOINTMENT OF EXECUTIVE SECRETARY; ADMINISTRATIVE STAFF AND SUPPORT.**—The Secretary, acting through either the Assistant Secretary for Health or the Director of the National Institute on Aging, shall appoint an Executive Secretary for the Task Force and shall provide the Task Force with such administrative staff and support as may be necessary to enable the Task Force to carry out its functions.

(f) **COMPENSATION AND EXPENSES.**—

(1) **COMPENSATION.**—Members of the Task Force who are not regular full-time employees of the United States government shall, while attending meetings and conferences of the Task Force or otherwise engaged in the business of the Task Force (including traveltime), be entitled to receive compensation at a rate fixed by the Secretary, but not exceeding the rate specified at the time of such service under GS-18 of the General Schedules established under section 5332 of title 5, United States Code.

(2) **EXPENSES.**—While away from their homes or regular places of business on the business of the Task Force, members of such Task Force may be allowed travel expenses, including per diem in lieu of subsistence, as is authorized under section 5703 of title 5, United States Code, for persons employed intermittently in the Government service.

SEC. 302. DUTIES.

The Task Force shall—

(1) coordinate research conducted by or through the Department of Health and Human Services and other Federal agencies concerning conditions and diseases leading to dependence among older Americans, and conditions and diseases leading to an increased need for long-term care.

(2) establish a mechanism for the sharing and dissemination of information among all officers and employees of the agencies participating on the Task Force and for the dissemination of information to health professionals and the public;

(3) identify the most promising areas of research concerning diseases and behavioral and social conditions leading to dependence among older Americans;

(4) establish mechanisms to use the results of research concerning the conditions and diseases leading to dependence among older Americans in the development of policies, programs, and means to improve the quality of life for older Americans; and

(5) review and evaluate public and private spending on such research.

SEC. 303. REPORTS TO CONGRESS.

Not later than 1 year after the date of enactment of this Act, and annually thereafter, the Task Force shall prepare and submit, to the appropriate Committees of Congress, and make available to the public, a report concerning—

(1) the progress made through research sponsored by the Federal Government concerning the conditions and diseases leading to dependence among older Americans, and increased need for long-term care.

(2) the new directions in research on such conditions and diseases which the Task Force considers potentially important; and

(3) recommendations for resource allocations.

SEC. 304. AUTHORIZATION OF APPROPRIATIONS.

There are authorized to be appropriated to carry out this title, \$150,000 for each of the fiscal years 1991 through 1993.

TITLE IV—CLAUDE D. PEPPER OLDER AMERICANS INDEPENDENCE CENTERS

SEC. 401. ESTABLISHMENT OF INDEPENDENCE CENTERS.

Section 445A of the Public Health Service Act (42 U.S.C. 285e-3) is amended to read as follows:

"SEC. 445A. CLAUDE D. PEPPER OLDER AMERICANS INDEPENDENCE CENTERS.

"(a) AGREEMENTS AND GRANTS.—The Director of the National Institute on Aging shall enter into cooperative agreements with, and make grants to, public and private nonprofit entities for the development of not less than 10 comprehensive centers of excellence, to be known as the Claude D. Pepper Older Americans Independence Centers, for the conduct of research, and for training, demonstration and dissemination of information concerning the application of such research, as provided for in this section.

"(b) DUTIES.—Each center developed or expanded under this section shall—

"(1) utilize the facilities of a single institution, or be formed from a consortium of cooperating institutions, meeting such research and training qualifications as may be prescribed by the Director;

"(2) be a comprehensive center including research, training, demonstration and dissemination activities related to enhancing the independence of older Americans;

"(3) be affiliated with one or more long-term care providers, including the full range of institutional and home and community-based providers; and

"(4) conduct—

"(A) research to evaluate the safety, effectiveness and cost of promising and innovative interventions aimed at promoting the independence of older Americans;

"(B) research into the aging processes and into the diagnosis, treatment, and rehabilitation of diseases, disorders, and complications related to aging which reduce the ability of older Americans to live independently;

"(C) research into menopause and other special considerations of aging women, including conditions, disorders, and complications that impair the independence of older women;

"(D) programs to develop individuals capable of conducting research concerning aging and concerning such diseases, disorders, and complications; and

"(E) training of health care and other professionals and paraprofessionals associated with the Centers in investigative approaches that are found to promote independence and disseminate this information to the public through appropriate educational and demonstration projects.

"(c) COORDINATION.—The Director of the National Institute on Aging shall assure that there is appropriate coordination between the Centers and—

"(1) other centers that receive assistance from the National Institutes of Health that are carrying out similar activities related to the reduction of dependency among older individuals; and

"(2) other governmental units with primary responsibility for—

"(A) the training of health care professionals and other paraprofessionals in acute and chronic care methods that promote independence; and

"(B) the conduct of research and demonstration of public education and prevention programs to improve the health and independence of older Americans.

"(d) AUTHORIZATION OF APPROPRIATIONS.—There are authorized to be appropriated to carry out this section, \$20,000,000 for fiscal year 1991, and such sums as may be necessary for each of the fiscal years 1992 and 1993."

I. SUMMARY OF THE BILL

The purpose of S. 2602 is to combat the major diseases and conditions that impair the independence of older Americans and their families, particularly Alzheimer's disease and related dementias, as well as to reach out to Alzheimer victims and their families with needed support, education and services.

With the skyrocketing cost of health care for the elderly and the rapidly growing number of older Americans, this legislation is expected to help stave off financial ruin of both our public health system and family pocketbooks. It will, in addition, afford greater independence and dignity and help reduce the needless suffering of those with Alzheimer's disease and those older Americans with other chronically disabling conditions.

Innovative research programs established and expanded under this bill will help develop an accurate and inexpensive tool to diagnose Alzheimer's disease, which would result in a yearly savings of \$1 billion in Medicare evaluation costs, and most effective means of treating, preventing and eventually curing Alzheimer's disease. An estimated four million Americans now suffer from Alzheimer's disease, and this number is expected to double in the next decade and increase to 14 million by the middle of the next century. The Committee believes that it is imperative to hasten the progress in combatting this devastating disease.

Debilitating illnesses and conditions are robbing older Americans of their health, independence and income. The costs of health and long-term care needed by older Americans will soar as our population ages in the decades to come. Older Americans are now spending a record amount out of their own pockets for health and long-term care. In 1988, these costs drained \$2,400 from the average person age 65 or older. That is eight times more than older Americans were forced to spend in 1966 when Medicare began. By the year 2030, the number of Americans who are 65 and older will double from its current 32 million. The fastest growing segment of this age group, those age 85 and older, will grow five-fold, from 2.5 million to approximately 12 million, over the same period of time.

The Research on Alzheimer's Disease and Independence for Older Americans Act of 1990 includes four separate titles: Research on Alzheimer's Disease and Related Disorders; Alzheimer's Disease State Programs; the Task Force on Aging Research; and the Claude D. Pepper Older Americans Independence Centers.

To complement and expand the work of the existing 15 Alzheimer's Disease Research Centers, title I of the bill creates Core Center grants to university medical centers for multidisciplinary

Alzheimer research. The bill also establishes satellite clinics for diagnostic and treatment service and research on Alzheimer's disease. These clinics are targeted to rural, minority and other underserved populations.

In an effort to reach out to Alzheimer's patients and their families, title II of the bill reauthorizes and expands the Alzheimer's disease grant program originally authorized in 1987 as part of the Older Americans Act. Under the program, states coordinate the development and operation of services (such as diagnosis, treatment, care management, respite care, legal counseling, and education for the patients, their families and caregivers) with public and private organizations.

To coordinate all Federally sponsored research on conditions and diseases leading to dependence among the elderly and to identify the most promising areas of research in this area, title III establishes the Task Force on Aging Research. The Task Force will be composed of: officials from the Department of Health and Human Services; the Chief Medical Officer of the Department of Veteran's Affairs; the Commissioner of the Social Security Administration; 2 Members from the House; 2 Members from the Senate; and 3 members of the general public.

Title IV will establish at least 10 Claude D. Pepper Older Americans Independence Centers to develop and carry out research on promising and innovative approaches and interventions designed to enhance the independence of older Americans and help ensure their continued productivity. The Centers are intended to reduce the impact and need for long-term care through the investigation of practical and creative steps to sustain independence and to subsequent translation and dissemination of these research findings to providers of care and the general public.

II. HISTORY OF LEGISLATION

The bill was offered by Senators Metzenbaum and Harkin as a substitute adapted from S. 2602 the "Comprehensive Alzheimer's Assistance, Research, and Education Act of 1990" (offered by Senator Metzenbaum and cosponsored by Senators Pressler, Grassley, Hatfield, Graham, Bradley, Durenberger, Adams, Simon, Heinz, Cranston, Biden, Jeffords, Harkin, Rockefeller, Kohl and Mikulski) and from S. 2654 the "Independence for Older Americans Act" (offered by Senator Harkin and cosponsored by Senators Hatfield, Sasser, Metzenbaum, Pell, Kerry, and Akaka) and as amended by Senator Adams.

On April 3, 1990, the Senate Labor and Human Resources Subcommittee on Aging and the House Select Committee on Aging held a joint hearing entitled, "Alzheimer's: The Unmet Challenge for Research and Care."

At the hearing, Dr. T. Franklin Williams, Director of the National Institute on Aging in Bethesda, Maryland, said that Federal researchers have only enough money to test one of sixteen new promising drugs for the treatment of Alzheimer's disease. He noted nearly half of all people in their 80's and 90's are expected to develop the disease.

Individuals whose family members have been afflicted with Alzheimer's disease spoke of the toll the disease exacts on victims and their families, and pleaded for increased Federal funding for research on the disease and care for its victims.

The family members testifying were: actresses Angie Dickinson and Shelley Fabares; William Gold of Farmington Hills, Michigan; Hilda Pridgeon of Bloomington, Minnesota, board member of the Alzheimer's Association; and Senator Mark Hatfield of Oregon.

III. BACKGROUND AND NEED FOR THE LEGISLATION

Because of its critical size and tragic impact, Alzheimer's disease is rapidly becoming one of the most serious threats to this nation's health and well-being. Yet despite its nationwide impact, for too long Alzheimer's disease has been a problem unpleasant to mention, easy to postpone, and despairing of solution.

While many major diseases are beginning to give ground to scientific research, progress on Alzheimer's disease lags behind. According to a recent study sponsored by the National Institute on Aging (NIA), an estimated 4 million Americans suffer from Alzheimer's disease, or about 10 percent of all persons over age 65 and nearly 50 percent of individuals over age 85. The Committee has found that other factors underscore the growing threat of Alzheimer's disease:

The NIA projects that the Alzheimer population will double over the next two decades, and strike as many as 14 million Americans by the middle of the next century;

The cost of Alzheimer's disease is approximately \$90 billion annually;

Recent surveys have revealed that as many as two-thirds of nursing home residents suffer from Alzheimer's disease and related disorders;

Although substantial progress has been made in recent years in identifying possible leads to the causes of Alzheimer's disease and related dementias and more progress can be expected in the near future, given adequate research funding, the research community may find itself on the verge of a breakthrough in the foreseeable future which would eliminate or substantially reduce the number of individuals with such disease and dementias or the difficulties of caring for such individuals;

Attempts to reduce the emotional and financial burden of caring for dementia patients is impeded by a lack of knowledge about such patients, how to care for such patients, the costs associated with such care, the effectiveness of various modes of care, the quality and type of care necessary at various stages of the disease, and other appropriate services that are needed to provide quality care;

The results of the research that has been undertaken concerning dementia has been inadequate or the results have not been widely disseminated;

More knowledge is needed concerning:

The epidemiology of, and the identification of risk factors for, Alzheimer's disease and related dementias;

The development of methods for early diagnosis, functional assessment, and psychological evaluation of individuals with Alzheimer's disease for the purpose of monitoring the course of the disease and developing strategies for improving the quality of life for such individuals and their families or caregivers. Such assessment also would be of great benefit to individuals suffering from other diseases prevalent among the elderly, such as Parkinson's disease;

The understanding of optimal methods to combine formal support services provided by health care professional with informal support services provided by family, friends, and neighbors of individuals with Alzheimer's disease, and the identification of ways family caregivers can be sustained through respite care and other interventions to reduce psychological, social and physical problems induced by stress.

The anguish suffered both by those afflicted and by their families transcend statistics. During an April 3, 1990 hearing on the subject, the Committee heard compelling testimony from family members who had endured the prolonged agony of seeing loved ones stripped of their mental and physical capacities.

Without a comprehensive long-term care system to turn to, they and millions of other family members are left to shoulder immense physical, emotional, and financial burdens. Unable to locate and arrange appropriate home and community-based services, most families are forced to turn to nursing home facilities for relief. If 10 percent of Alzheimer patients now in nursing homes had alternative home or community-based care, we would save \$8.8 billion annually. As a matter of health and social policy, premature placement in nursing home should be avoided.

Because of its cross-cutting nature, over 20 Federal departments, agencies, bureaus, and divisions conduct or fund aging research. Although the National Institute on Aging is the leader in this field, millions of dollars of research on aging and older Americans is conducted by the Social Security Administration, the Department of Veterans Affairs, the Health Care Financing Administration and the Alcohol, Drug and Mental Health Administration and many others. Yet, there is no adequate mechanism to assure that the research conducted by these divergent governmental units is coordinated. Regular coordination among the many agencies would provide an opportunity for improved efficiency and effectiveness. Such a coordinating mechanism in the form of a Task Force on Aging Research is created by this legislation.

While death rates among older individuals from acute conditions have decreased dramatically over the past 50 years, chronic conditions which inhibit independence and often lead to the need for long-term care are now the prevalent health care problem for older Americans and will increase greatly during the next century. If no action is taken, it is estimated that the number of older Americans needing nursing home care will more than triple, from 1.5 million to 5.3 million by the year 2030. The costs of this care would be enormous.

Much can be done to reduce the need for long-term care through improved research, training and demonstration. Innovative interventions hold great hope for controlling spiralling costs. Despite

the promise of these efforts, we are not investing adequately in developing and testing innovative interventions. The Claude Pepper Older Americans Independence Centers authorized by this legislation, address this public policy shortcoming.

IV. COMMITTEE ACTION

On September 26, 1990, the Committee on Labor and Human Resources considered and adopted without objection an amendment in the nature of a substitute offered by Senators Metzenbaum and Harkin.

An amendment to the substitute including research into menopause and other special considerations of aging women was offered by Senator Adams and accepted without objection.

The Committee considered a motion to favorably report the bill as amended. The Committee agreed unanimously to the motion by voice vote.

V. COST ESTIMATE

U.S. CONGRESS,
CONGRESSIONAL BUDGET OFFICE,
Washington, DC, October 3, 1990.

Hon. EDWARD M. KENNEDY,
Chairman, Committee on Labor and Human Resources,
U.S. Senate, Washington, DC.

DEAR MR. CHAIRMAN: The Congressional Budget Office has prepared the attached cost estimate for S. 2602, the Research on Alzheimer's Disease and Independence for Older Americans Act of 1990, as ordered reported by the Senate Committee on Labor and Human Resources on September 26, 1990.

If you wish further details on this estimate, we will be pleased to provide them.

Sincerely,

ROBERT D. REISCHAUER,
Director.

CONGRESSIONAL BUDGET OFFICE—COST ESTIMATE

1. Bill number: S. 2602.
2. Bill title: Research on Alzheimer's Disease and Independence for Older Americans Act of 1990.
3. Bill status: As ordered reported by the Senate Committee on Labor and Human Resources on September 26, 1990.
4. Bill purpose: To amend the Public Health Service Act to provide assistance for biomedical and health services research education, treatment programs and for other purposes relating to Alzheimer's disease and related disorders.
5. Estimated cost to the Federal Government:

[By fiscal years, in millions of dollars]

	1991	1992	1993	1994	1995
Estimated authorization levels:					
Alzheimer's research grants.....	40	42	43		

[By fiscal years, in millions of dollars]

	1991	1992	1993	1994	1995
Alzheimer's demonstrations.....	20	21	22		
Claude D. Pepper Centers.....	20	21	22		
Task Force on Aging Research.....	(¹)	(¹)	(¹)		
Total estimated authorization levels.....	80	83	87		
Total estimated outlays.....	25	73	84	59	9

¹ Less than \$500,000.

Details in the table may not add to totals because of rounding. The costs of this bill fall within budget function 550.

Basis of estimate: S. 2602 would authorize \$40 million in fiscal year 1991 and such sums as may be necessary in each of fiscal years 1992 and 1993 to assist university medical centers to develop innovative research relating to the diagnosis and treatment of Alzheimer's disease. The bill would authorize \$20 million in fiscal year 1991 and such sums as may be necessary in each of fiscal years 1992 and 1993 to fund between 3 and 10 demonstration projects that would provide care to individuals with Alzheimer's disease. The bill would also authorize \$20 million in 1991 and such sums as may be necessary in 1992 and 1993 to develop at least 10 centers, to be known as the Claude D. Pepper Older Americans Independence Centers, that would conduct research, training, and demonstrations related to enhancing the independence of older Americans. CBO estimated the 1992 and 1993 authorization levels for each of these programs by adjusting their respective 1991 authorization for projected inflation.

S. 2602 would authorize the Secretary of Health and Human Services to establish a task force on aging research. The bill would authorize \$150,000 in each of fiscal years 1991 to 1993 in order to support an executive secretary and additional staff for the task force and to compensate members of the task force who are not full-time employees of the United States government.

This estimate assumes that all authorizations are fully appropriated at the beginning of each fiscal year. Outlays are estimated using spendout rates computed by CBO on the basis of recent program data.

6. Estimated cost to State and local government: In order to receive grants for demonstration projects relating to Alzheimer's disease, states would have to provide 25 percent of the program costs in 1991, 35 percent of the program costs in 1992, and 45 percent of the program costs in 1993. If all of the grants authorized are appropriated and awarded, state governments would have to contribute about \$7 million in 1991, \$11 million in 1992, and \$18 million in 1993.

7. Estimate comparison: None.

8. Previous CBO estimate: On August 15, 1990, CBO prepared a cost estimate of S. 2602, the Comprehensive Alzheimer's Assistance, Research, and Education Act of 1990, as introduced and referred to the Senate Committee on Labor and Human Resources on May 9, 1990.

9. Estimate prepared by: Karen Graham.

10. Estimate approved by: C.G. Nuckols (for James L. Blum, Assistant Director for Budget Analysis).

VI. REGULATORY IMPACT ANALYSIS

This legislation is not expected to have any regulatory impact or impact on any regulatory agency.

VII. COMMITTEE VIEWS

Five years ago, this committee recommended that establishment of a network of centers to carry out a multidisciplinary research program in Alzheimer's Disease. To date, fifteen Alzheimer's Disease Research Centers (ADRCs) have been established, each of which has contributed important new information about the disease.

In Title I, the Committee is recommending that two programs be authorized to help strengthen and complement the work of the ADRCs: core center grants and satellite clinics.

Core center grants would support administrative and clinical units and university medical facilities. Unlike the ADRCs, core center grants would not directly support full-scale research, but would provide the research resources, e.g. well characterized patient information, family histories and tissue samples, and brain tissue of Alzheimer patients and control studies, required to carry out research at the 15 ADRCs. These units might be called upon to collect patient data, carry out pilot testing, or serve as one of many clinical trial sites.

The Committee also sees the need to extend state-of-the-art clinical services through the ADRCs to rural, minority and other underserved populations. By authorizing grants for satellite clinics, the Committee expects the ADRCs to offer the latest diagnostic and treatment techniques to these underserved populations and, at the same time, provide clinical research experience to physicians, nurses and social workers outside the environment of a university medical center. Expanding the Alzheimer's patient base and overall reach of the ADRCs is an essential and cost-effective method to unlock the mystery of this cruel killer. The Committee recommends an authorization of \$40,000,000 to carry out both programs.

While research holds the key for the future, we must not ignore the needs of families struggling to care for Alzheimer patients at home. The urgency of the need for programs to help provide essential home services for Alzheimer patients and families is underscored by a recent report the Committee requested from the Office of Technology Assessment.

OTA's report, entitled, "Confused Minds, Burdened Families," documents the devastation of Alzheimer's Disease:

* * * over time the affected individual becomes less able to function independently and more dependent on others for care * * *. As a dementia patient's condition worsens, his or her family and friends are faced with severe emotional losses * * *. They are faced simultaneously with the person's need for supervision, physical care, and many

other kinds of assistance to compensate for his or her lost abilities.

The OTA report documents the lack of sufficient appropriate services that are affordable or reimbursable, and the complexity and fragmentation of services that do exist. OTA calls for the combined efforts of public and private agencies and organizations to provide: high-quality services by well-trained individuals; adequate funding; and effective methods for locating and arranging services.

To this end, the Committee recommends a three-year extension of authority under Title III of the Public Health Service Act for a pilot program of matching grants to States for Alzheimer demonstration projects. Pilot projects would include: (1) coordination of existing State programs for Alzheimer patients and families; (2) support for respite care programs; and (3) information networks linking families to available services.

As the OTA report points out, an estimated 70 percent to 80 percent of all Alzheimer patients remain at home, where the responsibility for care usually falls to an elderly spouse or adult child. The OTA report and testimony from family members time and again emphasize the need for respite services.

The Committee finds that there are more than 20 units within the Federal government that conduct or support aging research. Yet, there is no effective mechanism to oversee these efforts so as to ensure appropriate coordination and avoid unnecessary duplication. There is also a need to commonly identify and disseminate promising areas of aging research that will be expected to promote the independence of older Americans and reduce the cost of long-term care.

The Committee recognizes the need for a Federal Task Force on Aging Research under the leadership of the Secretary of Health and Human Services and the National Institute of Aging of the National Institutes of Health. Section 304 of Title III authorizes \$150,000 for each of the fiscal years 1991 through 1993 for the Task Force on Aging Research. The Committee is aware of the need for support of the work of the Task Force so that it may carry out its responsibilities for interagency coordination, information sharing, the identification of promising areas of research and the establishment of mechanisms leading to utilization of research results. For these purposes, the Committee expects that a full-time Executive Secretary and staff position will be supported directly by these additional resources, to be supplemented by the agency members of the Task Force as may be requested by the Chairman or Executive Secretary. The Committee also expects active and high-level participation from the governmental agencies represented on the Task Force and looks forward to reviewing their report.

The Committee concurs with the recommendations of The Pepper Commission emphasizing the importance of research aimed at enhancing the functional capacity and productivity of older Americans. A variety of diseases and conditions attending the aging process take a steady toll in forcing our older citizens and their families to resort to dependent and costly long-term care services. While basic investigations continue to be required to unravel the fundamental aspects of aging, more immediately applicable re-

search is also needed to translate our current knowledge into substantive benefits.

The National Institute of Aging is currently able to support only two Geriatric Research and Training Centers while six other meritorious Centers were not funded due to lack of resources. The Committee recognizes the need for expanding the numbers and scope of existing efforts by emphasizing quality research of promising interventions that are likely to result in self-sufficiency in activities of daily living (eating, dressing, bathing, toileting, ambulation) among the elderly so as to promote their continued involvement and productivity within the family and society. The Committee further recognizes that the outcomes of these research efforts should be translated to the clinical care setting by the appropriate dissemination of the new knowledge and the training of professionals and paraprofessionals. The Committee has recommended authorization of \$20,000,000 in fiscal year 1991 and such sums as necessary in fiscal years 1992 and 1993 for the establishment and operation of not less than 10 Claude D. Pepper Older Americans Independence Centers.

The Committee emphasizes that a broad range of investigations will be conducted at the Claude D. Pepper Independence for Older Americans Centers including research into menopause and other conditions, disorders and complications that particularly impair the independence of older women. The Committee is concerned that little attention has been paid to menopause and its potential implications for women's health. Menopause is a fundamental fact of aging for women, yet is not listed by the National Institute of Aging as an area of study in its research programs relevant to the health of older women. The Committee believes that research into menopause is a critically important aging issue: a woman today can expect to spend the last third of her life in the postmenopausal years. Serious medical and quality of life issues concerning menopause need to be addressed, particularly about the implications of hormone replacement therapy and the onset and treatment of diseases like breast cancer and heart disease.

VIII. SECTION-BY-SECTION ANALYSIS

TITLE I. RESEARCH CONCERNING ALZHEIMER'S DISEASE AND RELATED DISORDERS

Section 101 requires the Director of the National Institute on Aging to take the following actions to complement and expand the program of the Alzheimer's Disease Research Centers authorized in section 445 of the Public Health Service Act:

(1) award Core Center Grants to university medical centers to encourage and to facilitate the development of multidisciplinary research concerning Alzheimer's Disease and encourage investigators to enter into the field of Alzheimer's Disease research. Such grants shall be used to support:

(A) patient assessment units that facilitate clinical research and the development of new treatment techniques including clinical drug trials;

(B) patient registries and tissue and brain banks from Alzheimer's Disease patients and control studies;

- (C) the training of new investigators;
- (D) public education and information dissemination; and
- (E) collaboration between institutions for research and other activities.

The Director also shall:

- (2) enter into grants, contracts or cooperative agreements with the Alzheimer's Disease Research Centers established under Section 445, or entities receiving financial assistance under paragraph (1), for the division of diagnostic and treatment service and research for Alzheimer's Disease and related disorders at Satellite Clinics, such clinics to be targeted to minority, rural or other underserved populations.

This section requires that each entity desiring to receive a grant or enter into a cooperative agreement under this section shall prepare and submit to the Director or the Institute an application each time, in such manner, and containing such information as the Director may require.

There are authorized to be appropriated \$40,000,000 in fiscal year 1991, and such sums as necessary in each of fiscal years 1992 and 1993 to carry out this title.

TITLE II. EXTENSION OF PROGRAM REGARDING ALZHEIMER'S DISEASE

In extending and expanding the program regarding Alzheimer's Disease, Section (a)(1) amends Section 398(a) of the Public Health Service Act so that the Secretary shall make not less than eight nor more than 15 grants.

Section (2) affects coordination of services by amending Section 398(a)(1) of the Act by striking "by public and private organizations" and inserting "with public and private organizations."

Section (3) establishes new authorization levels for the program by amending Section 399(a) of the Act by striking "there is" and inserting "there are" and inserting "\$20,000,000 for fiscal year 1991, and such sums as may be necessary for each of the fiscal years 1992 and 1993".

The amendments made by this section shall take effect on October 1, 1990, or on the date of enactment of this Act, whichever occurs later.

TITLE III. TASK FORCE ON AGING RESEARCH

Section 301 requires the Secretary of the Department of Health and Human Services to establish a Task Force on Aging Research to enhance the coordination of federally supported aging research. It also prescribes the membership of the Task Force as well as requirements for the selection of a chairperson, constitution of a quorum and meetings of the Task Force, the appointment of staff for the Task Force and the compensation and expenses of Task Force members.

Section 302 outlines the duties of the Task Force as follows:

- (1) coordinating Federally supported research concerning conditions and diseases leading to dependence among older Americans and those leading to an increased need for long-term care;

(2) establishing a mechanism for the sharing and dissemination of information among and to agencies participating on the Task Force and dissemination of information to health professionals and the general public;

(3) identifying the most promising areas of research concerning disease and conditions leading to dependence among older Americans;

(4) establishing mechanisms to use the results of relevant research in the development of policies and programs to improve the quality of life for older Americans; and

(5) reviewing and evaluating public and private spending on such research.

Section 303 requires the Task Force to annually prepare, submit to Congress and make available to the public a report concerning progress made through Federally supported research in this area, as well as ideas for new promising research directions, and recommendations for resource allocations.

Section 304 authorizes \$150,000 to be appropriated in each of fiscal years 1991, 1992, and 1993 to carry out this title.

TITLE IV. CLAUDE D. PEPPER OLDER AMERICANS INDEPENDENCE CENTERS

Section 401 amends Section 445A of the Public Health Service Act to provide for the establishment of Claude D. Pepper Older Americans Independence Centers as follows:

Subsection (a) requires the Director of the National Institute on Aging (hereafter referred to as the "Director") to establish not less than 10 comprehensive centers of excellence, to be known as the Claude D. Pepper Older Americans Independence Centers, for the conduct of research, training, demonstration and dissemination of information concerning such research as provided for in this section.

Subsection (b) prescribes the duties of such centers. Each center developed or expanded under this section is to:

(1) Utilize the facilities of a single institution, or be formed from a consortium of cooperating institutions, meeting qualifications as may be prescribed by the Director;

(2) Be a comprehensive center including research, training, demonstration and dissemination activities related to the enhancing the independence of older Americans;

(3) Be affiliated with one or more long-term care providers; and

(4) Conduct research to evaluate the safety, effectiveness and cost of promising and innovative interventions aimed at promoting independence of older Americans; research into the aging process and the diagnosis, treatment and rehabilitation of diseases, disorders and complications related to aging which reduce the ability of older Americans to live independently; research into menopause and other special considerations of older women that impair independence; programs to develop researchers in these areas; and training of professionals and paraprofessionals associated with the Centers in investigative

approaches that are found to promote independence and dissemination of this information to the public.

Subsection (c) requires the Director to assure that there is appropriate coordination between the Centers and other centers with related responsibilities sponsored by the National Institutes of Health and other governmental units with primary responsibility for training of professionals and paraprofessionals in acute and chronic care methods that promote independence of older Americans and for the conduct of public education and demonstration programs to improve the health and independence of older Americans.

Subsection (d) authorizes to be appropriated to carry out this title \$20,000,000 in fiscal year 1991 and such sums as necessary in fiscal years 1992 and 1993.

IX. CHANGES IN EXISTING LAW

In compliance with rule XXVI paragraph 12 of the Standing Rules of the Senate, the following provides a print of the statute or the part or section thereof to be amended or replaced (existing law proposed to be omitted is enclosed in black brackets, new matter is printed in italic, existing law in which no change is proposed is shown in roman):

PUBLIC HEALTH SERVICE ACT

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SEC. 398. ESTABLISHMENT OF PROGRAM.

(a) IN GENERAL.—The Secretary [shall make not less than 3, and not more than 5, grants] *shall make not less than eight nor more than 15 grants* to States for the purpose of assisting grantees in carrying out demonstration projects for planning, establishing, and operating programs—

(1) to coordinate the development and operation [by public and private organizations] *with public and private organizations* of diagnostic, treatment, care management, respite care, legal counseling, and education services provided within the State to individuals with Alzheimer's disease or related disorders and to the families and care provides of such individuals;

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SEC. 399A. GENERAL PROVISIONS.

(a) * * *

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(e) AUTHORIZATIONS OF APPROPRIATIONS.—For the purpose of carrying out this subpart, [there is] *there are* authorized to be appropriated \$5,000,000 for each of the fiscal years 1988 through 1990. *\$20,000,000 for fiscal year 1991, and such sums as may be necessary for each of the fiscal years 1992 and 1993.*

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CENTERS OF GERIATRIC RESEARCH AND TRAINING

[SEC. 445A. [285e-3]] (a) The Director of the Institute shall enter into cooperative agreements with, and make grants to, public and private nonprofit entities for the development or expansion of centers of excellence in geriatric research and training of researchers.

[(b)] Each center developed or expanded under this section shall—

[(1)] utilize the facilities of a single institution, or be formed from a consortium of cooperating institutions, meeting such research and training qualifications as may be prescribed by the Director; and

[(2)] conduct—

[(A)] research into the aging processes and into the diagnosis and treatment of diseases, disorders, and complications related to aging; and

[(B)] programs to develop individuals capable of conducting research concerning aging and concerning such diseases, disorders, and complications.

[(c)] In making cooperative agreements and grants under this section for the development or expansion of centers, the Director of the Institute shall ensure that, to the extent practicable, any such centers are distributed equitably among the principal geographic regions of the United States.]

SEC. 445A. CLAUDE D. PEPPER OLDER AMERICANS INDEPENDENCE CENTERS.

(a) AGREEMENTS AND GRANTS.—The Director of the National Institute on Aging shall enter into cooperative agreements with, and make grants to, public and private nonprofit entities for the development of not less than 10 comprehensive centers of excellence, to be known as the Claude D. Pepper Older Americans Independence Centers, for the conduct of research, and for training, demonstration and dissemination of information concerning the application of such research, as provided for in this section.

(b) DUTIES.—Each center developed or expanded under this section shall—

(1) utilize the facilities of a single institution, or be formed from a consortium of cooperating institutions, meeting such research and training qualifications as may be prescribed by the Director;

(2) be a comprehensive center including research, training, demonstration and dissemination activities related to enhancing the independence of older Americans;

(3) be affiliated with one or more long-term care providers, including the full range of institutional and home and community-based providers; and

(4) conduct—

(A) research to evaluate the safety, effectiveness and cost of promising and innovative interventions aimed at promoting the independence of older Americans;

(B) research into the aging processes and into the diagnosis, treatment, and rehabilitation of diseases, disorders, and complications related to aging which reduce the ability of older Americans to live independently;

(C) research into menopause and other special considerations of aging women, including conditions, disorders, and complications that impair the independence of older women;

(D) programs to develop individuals capable of conducting research concerning aging and concerning such diseases, disorders, and complications; and

(E) training of health care and other professionals and paraprofessionals associated with the Centers in investigative approaches that are found to promote independence and disseminate this information to the public through appropriate educational and demonstration projects.

(c) **COORDINATION.**—The Director of the National Institute on Aging shall assure that there is appropriate coordination between the Centers and—

(1) other centers that receive assistance from the National Institutes of Health that are carrying out similar activities related to the reduction of dependency among older individuals; and

(2) other governmental units with primary responsibility for—

(A) the training of health care professionals and other paraprofessionals in acute and chronic care methods that promote independence; and

(B) the conduct of research and demonstration of public education and prevention programs to improve the health and independence of older Americans.

(d) **AUTHORIZATION OF APPROPRIATIONS.**—There are authorized to be appropriated to carry out this section, \$20,000,000 for fiscal year 1991, and such sums as may be necessary for each of the fiscal years 1992 and 1993.

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DISSEMINATION PROJECT

SEC. 445F. (a) * * *

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SEC. 445G. ALZHEIMER RESEARCH CENTER CORE GRANTS.

(a) **IN GENERAL.**—To complement and expand the program of the Alzheimer's Disease Research Centers authorized in section 445, the Director of the National Institute on Aging shall—

(1) award Core Center Grants to university medical centers to encourage and to facilitate the development of innovative multidisciplinary research concerning Alzheimer's Disease and encourage investigators to enter into the field of Alzheimer's Disease research, such grants shall be used to support—

(A) patient assessment units that facilitate clinical research and the development of new treatment techniques including clinical drug trials;

(B) patient registries and Alzheimer's Disease patient tissue and brain banks and control studies;

(C) the training of new investigators;

(D) public education and information dissemination; and

(E) support collaboration between institutions for research and other activities; and

(2) enter into grants, contracts or cooperative agreements with Alzheimer's Disease Research Centers established under section 445, or entities receiving financial assistance under paragraph (1), for the provision of diagnostic and treatment service and research for Alzheimer's Disease and related disorders at Satellite Clinics, such clinics to be targeted to minority, rural or other underserved populations.

(b) APPLICATION.—Each entity desiring to receive a grant or enter into a cooperative agreement under this section shall prepare and submit, to the Director of the Institute, an application at such time, in such manner and containing such information as the Director may reasonably require.

(c) AUTHORIZATION OF APPROPRIATIONS.—There are authorized to be appropriated to carry out this section, \$40,000,000 for fiscal year 1991, and such sums as may be necessary in each of the fiscal years 1992 and 1993.

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